

# How to evaluate Quality of Life

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## Abstract

In medical terminology, it has become more and more common the use of the expression “Quality of Life” (QoL) to define a series of aspects that go beyond the traditional, clinical and “objective” evaluation of the medical intervention. The attention to QoL comes from the need to find tools that are able to reveal important aspects of the life of the patient that cannot be measured by a laboratory exam and/or a radiological procedure. The QoL is measured through multidimensional questionnaires on, at the very least, the domains of physical, psychological and social health. The improvement of the health care standards and the technological progress in medical matters have brought about an increase in the average age of the population, and as a consequence, an increase of the chronic and degenerative disease, which can negatively influence the patient’s quality of life. Amongst these pathologies, heart failure (HF) has a high prevalence in patients who are at least 70 years old, and it’s the cause of frequent and repeated hospitalizations. The estimate of the QoL becomes then a very important piece of the puzzle to figure out, as important as the clinical parameters, to allow the patient to become an integral part of the physician’s decisions and to reach more quickly and with better results the therapeutic objectives.

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## Introduction

It is now becoming more and more frequent to encounter the expression “quality of life” (QoL) in the articles of medical literature, along with articles in the most famous Italian and foreign newspapers, such as “Il Sole 24 ore” in a 2017 review on the topic of livability in Italy. Already the ancient Egyptians in the Valley of Kings and the Babylonians wished for an improvement of quality of life after death, compared to that which was achieved during life [1]. Today’s concept of quality of life started from the definition of health given in 1948 by the World Health Organization (WHO), which defined it not only as the absence of infirmity or disease, but as a state of complete physical, mental and social wellbeing. Later on, in 1995 WHO proposed the conceptualization of QoL as the subjective perception that the individual has of their position in life, in the context of the cultural systems and of the set of values in which they live, and also in relation to their objective, expectations, standards and interests [2]. In the literature is possible, also, to find the concept of Health-Related Quality of Life (HRQoL), defined as the totality of the qualitative aspects of the individual’s life related to the domains of disease and health and, therefore, that can be acted upon in health care. Often QoL and HRQoL are thought, erroneously, to be synonyms. It doesn’t, however, exist a single definition of QoL. Keeping this in mind, the term health moves from the mere biological plane to embrace aspects of the social, emotional and relational life which are a priority for the patient.

There is also a re-conceptualization of the state of health which, from the purely objective such as the physician’s findings, moves to a more subjective and introspective domain: the point of view of the patient. It is clear that to quantify the subjective wellbeing of an individual is an undertaking that’s anything but easy and uncomplicated. In 1995 Wilson and Cleary described a conceptual model of QoL, highlighting the essential aspects to identify tools able to measure QoL [3]. This model is composed of five different levels, whose fundamental elements are that they have a subjective nature, namely self-evaluation; they are dynamic, as they vary in time based on several factors, multidimensional and culturally-related, intended to quantify QoL considering the physical, psychological and social functioning and wellbeing, and physical symptoms stemming from the pathology or from specific therapeutic interventions [3].

## Why measure QoL

An aspect that needs to be highlighted is the fact that the true revolution of health care in the last twenty years doesn't concern so much the discovery of the importance of the QoL of the patient, as much as the necessity measure the QoL in a more structured way and using tools designed exclusively for it. These tools allow to quantify objectively and later on, to intervene upon, the subjective unease that is responsible for the worsening of the QoL, with the final objective of evaluating it and, when possible, improving it.

## The tools

In common practice, QoL is measured through brief questionnaires; they can be roughly divided in the following categories: generic tools, specific tools, specific tools for particular areas of QoL, as shown in Table 1. The method to measure QoL has undergone a lot of fine-tuning, going from indirect and "primitive" parameters to others more and more sophisticated and focused on the patient's perspective.

Many questionnaires, self-administered or given by professionals, have been proposed to measure health from the patient's point of view. Professional figures, in relation to health settings (hospital rather than outpatient services), devoted to questionnaire administration and interpretation are usually physicians, nurses or health professionals and social workers.

As there is a great availability of such tools, it can be difficult to determine which might be the most appropriate in the specific context of application, and which might be most useful to the clinical or experimental purpose.

When choosing the tools, it is important to ascertain the real scientific solidity of the process used to create and validate the questionnaire, as well as to choose the tool that will provide a single and global index of the QoL perceived by the patient, keeping into consideration the population being examined and the pathology of the patient more than just a specific symptom to be examined singularly.

The category of generic tools allows to compare the health profiles of different groups of patients regardless of pathology, and thus they are not validated on specific populations of patients; they have a great versatility of application. The term "generic" might be interpreted as having a negative connotation, as lacking refinement and precision, but in this case, the term needs to be intended as "general".

Probably one of the most used tools in this group, because of its methodological efficacy, is the 36-item short form health survey by the RAND Corporation, better known by its acronym SF-36 [4], which focuses, through 36 questions, on the physical and mental/psychological state of the subject. It is available also a short-form version with 12 domains. Another greatly used generic tool is the EQ-5D, of the EuroQoL Group which is a network of multidisciplinary international researchers focused on measuring health, with members from Europe, North America, Asia, Africa, Australia and New Zealand [5].

In the category of specific instruments, we can find questionnaires developed to evaluate several aspects that can influence the QoL of patients who suffer from specific pathologies or that are undergoing specific treatments. Hundreds of tools have been developed to measure health and perceived QoL while suffering from several pathologies: cardiovascular, oncologic, dermatologic, immune system related and of the respiratory system, just to cite a few, in adult patients; furthermore, tools have been developed for children or adolescent patients. In the last thirty years, researchers in the field have been paying particular attention to chronic/degenerative illnesses and the elderly patient [6,7]. It is now taken as a given the idea that the doctor will have to assist more and more frequently older, comorbid patients. In this sense, comorbidity has to be interpreted not only as the simultaneous presence of more than one pathology, but also as the interaction of more noxae that determine a great variability in the evolution of the illnesses. According to our clinical experience, the factors that, more than others, influence the quality of life of the patient are the nutritional and affective state of the patient; it is then extremely useful to investigate these aspects in a systematic way, within the Comprehensive Geriatric Assessment (CGA). Amongst chronic illnesses, cardiovascular problems represent the first cause of death in the world, and they have considerable weight in terms of comorbidity; heart failure (HF) is one of the most important, for prevalence and incidence. In industrialized countries, the prevalence of HF is increasing because of the progressive aging of the population, caused by higher rates of survival and the efficacy of secondary prevention. In short, it is an illness with a huge impact on prognosis and on the lifestyle of the patients, and a growing challenge for physicians, being responsible for repeated hospitalizations and increase of health-related costs [7]. Specific tools to evaluate the QoL in patients suffering from HF provide the physician with a way to understand the influence that the

**Table 1. QoL tools that can be used in Heart Failure clinical management.**

Generic (general) tools	Specific tools	Specific tools for particular areas of QoL
- 36-item short form health survey (SF-36) - EQ-5D	- Minnesota living with heart failure questionnaire - Kansas City Cardiomyopathy Questionnaire" (KCCQ-12)	VAS scale (Visual Analog Scale)

pathology has on the daily life of the patient, and a useful parameter to develop more focused treatments [8]. Amongst these tools, the most frequently used are the “Minnesota living with heart failure questionnaire” [9,10] and the “Kansas City Cardiomyopathy Questionnaire” (KCCQ-12). Some of the factors that seem to exert the most influence on the QoL of stable HF outpatients and that are associated with a worse quality of life are the copresence of depressive symptoms, the advanced NYHA class (III-IV), youth and being female [11]. The multidisciplinary aspect of treatments, including palliative care, seems to be a winning strategy to improve QoL and spiritual well-being, and to reduce anxiety and depression in patients with advanced HF [12].

Finally, the category of specific tools for particular areas of QoL includes questionnaires that evaluate only specific aspects, regardless of the pathology of the patient, such as anxiety, depression, social support, pain or fatigue. Among these tools, it is well known the VAS scale (Visual Analog Scale) [13] which is a one-dimensional tool that is easily administered as it allows for the self-evaluation of pain intensity through a numeric scale.

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## Conclusions

In conclusion, the attention to the quality of life should be an integral part of the holistic evaluation of the patient, and be afforded the same importance as the anamnesis, pharmacological issues and illness' pathogenesis.

During the medical visit should also be highlighted, along with the biological and clinical parameters of the patient, also the patient's will, in relation to their standards of quality of life and the objectives and achievements they may want to reach in life. We believe this approach to be a winning one, that allows to create solid bases to develop a therapeutic alliance between physician and patient.

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